

“Sound Start” of Louisiana Early Hearing Detection and Intervention Program



Louisiana Hospitals’ Universal Newborn Hearing Screening Guidelines

**Department of Health and Hospitals
Office of Public Health, Hearing, Speech and
Vision Services**

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Program Goals

Early Hearing Detection and Intervention (EHDI) makes a significant difference in the lives of children who are Deaf or Hard of Hearing and their families. Recent studies have shown that the most significant predictor of normal language development in children with significant hearing loss is detection and intervention before six months of age. Hearing can be screened at any age using valid and reliable automated screening techniques. Universal newborn hearing screening is supported by national initiatives and policy statements such as Healthy People 2010, Maternal and Child Health Bureau objectives, the Joint Commission on Infant Hearing 2000, the Center for Disease Control, and the American Academy of Pediatrics.

The goal of this Hearing Screening Program is: To identify hearing impaired infants at the earliest possible time so that medical treatment, early audiological evaluation, selection of amplification, and early educational intervention can be provided.

Opportunity for Screening

The birth admission represents one of the few times when all but a small number of babies can easily be tested. Louisiana hospitals have recognized this opportunity and the need to identify hearing loss early. Hospital screening programs form the basis for all statewide early hearing detection efforts and 100% of all birthing hospitals in the state are legislatively mandated to perform universal newborn hearing screening as of April 1, 2002.

Why Guidelines Matter

As programs are newly formed or restructured from testing only high-risk infants, it has become apparent that there is a need for information and guidance to ensure that the screening results are valid and that programs run efficiently and effectively. This document provides guidelines and information that will be helpful in both establishing and maintaining newborn hearing screening programs.

Who developed the guidelines

The guidelines on the following pages were developed by regional task forces from around the state of Louisiana facilitated by the Sound Start program in collaboration with the Louisiana Office of Public Health and the State Advisory Council on Infant Hearing. These guidelines are based on the DHH rules and regulations developed to accompany Louisiana Act 653 of 1999 Legislation. Funding was provided in part by grants from the Maternal and Child Health Bureau and Center for Disease Control and Prevention. A list of task force participants can be found in Appendix B.

Basic Screening Requirements of Louisiana ACT 653 of 1999

- ❖ All birthing hospitals are required to perform a physiologic hearing screening on all infants born in or transported to their facility prior to hospital discharge.
- ❖ Screening must be performed only by appropriately trained and supervised professionals.
- ❖ Each hospital must report the results of the screening test to the office of Public Health, Primary Care Physician, and parents within 14 days.
- ❖ Infants who do not pass the screening must be referred to the primary care physician and an audiologist for follow-up within 7 days.

The following 8 principles of the Joint Committee on Infant Hearing, 2000 Position Statement provides a foundation for an effective program and are worthy goals for all service providers within our system:

- I. All infants will have access to a hearing screening using physiologic measures.
- II. All infants who do not pass the birth admission screen and any subsequent rescreening will begin appropriate audiologic and medical evaluations to confirm the presence of hearing loss before 3 months of age.
- III. All infants with confirmed permanent hearing loss will receive services before 6 months of age.
- IV. All infants who pass newborn screening but who have risk indicators for progressive loss will receive ongoing audiological, medical, and communication development monitoring.
- V. Infant and family rights will be guaranteed through informed choice, decision-making, and consent.
- VI. Infant hearing screening and evaluation results will be afforded the same protection as other health care and educational information.
- VII. Information systems will be used to measure and report the effectiveness of early hearing detection and intervention (EHDI) services.
- VIII. EHDI programs will provide data to monitor quality, demonstrate compliance, determine fiscal accountability and cost effectiveness, support reimbursement for services, and mobilize and maintain community support.

Hospital Hearing Screening Program Supervisor

Newborn hearing screening programs are complex and involve the management of many different aspects including staffing, policies and procedures, and communications with families, medical providers, and government agencies. To accomplish the goals of your program, responsibility should be clearly defined and delegated. Assigning a Hospital Hearing Screening Program Supervisor ensures that your program works more efficiently and effectively.

The Hospital Hearing Screening Program Supervisor is responsible for overseeing and managing the various aspects of your program. ***As mandated by the Department of Health and Hospital rules and regulations, this Hospital Program Supervisor must:***

- Be available by telephone while screening is taking place.
- Review a percentage of the screening documentation and DHH Newborn Screening Report Forms to determine if filled out appropriately.
- Determine that appropriate testing is being performed in quiet environment.
- Perform direct periodic observation of each individual at least once per month initially as they perform the hearing screen. After the screener has performed screening for one year, observation is necessary only once every 3 months.
- Monitor that hearing-screening equipment is calibrated annually.
- Monitor that infants failing hearing screening are appropriately referred to an Audiologist and Primary Care Physician for further testing within 7 days.

Other areas in which the Hospital Program Supervisor will be involved will include:

Management of state reporting

Determining Benchmarks and Quality Assurance measures are gathered and monitored

Management of staffing including training and monitoring

Management of equipment including determining type of technology and maintenance

Determining that proper Procedures and Protocols are in place

Creating or gathering culturally sensitive educational materials

Communicating program goals and accomplishments with medical providers

Communicating with families

Communicating with audiologists, early intervention agencies and other community providers to assure appropriate referrals

These areas will be discussed in the following section of the guidelines.

Choosing a Screening Method and Managing Equipment

One of the most important decisions on implementing a screening program is the choice of screening method. Any screening method chosen should measure a physiological response (not behavioral). Currently Otoacoustic Emissions (either transient or distortion products) and Auditory Brainstem Evoked Response are the methods of choice for universal newborn hearing screening programs. Your Hospital Program Supervisor should research the various equipment options based on the following:

- Initial Cost
- Anticipated refer rates
- Ongoing costs
- Ease of use
- Availability of customer service and support
- Warranty and service contract

Other considerations for technology choices include the following:

- Use of more than one technology
- Average length of stay
- Anticipated staffing patterns and personnel who will be using the equipment
- Birth Census
- Demographics of the community
- Likelihood of follow-up based on other health screenings (PKU, immunizations)
- Anticipated follow-up rate
- Screening and rescreening protocols

Several different types of screening equipment are available. Each of them can be part of a successful program although some characteristics may suit one program better than another. The per patient disposable costs are generally less for OAE's but they often have a higher initial refer rate, especially if the length of stay is less than 24 hours. Hospitals in remote areas where distance and transportation is an issue may need to implement procedures to ensure a very low initial refer rate.

Some equipment may be easier to learn how to operate or less complicated with respect to maintenance of skills. Ease of use can be an important consideration in staffing patterns, especially for hospitals with low birth volumes or those who choose to train large numbers of staff as screeners.

Management of State Reporting

Each hospital is required to fill out a form entitled “Newborn Hearing Screening Report” on each infant born or transferred into a birthing hospital. This form should be completely filled out including maternal maiden name and name of the infant if known. Any risk factors that are present are to be marked including a family history of hearing loss not due to illness. Hearing test results are to be filled in at the bottom of the form and signed by the person performing the testing.

If your hospital utilizes the electronic birth certificate:

The State of Louisiana has the capability to utilize the Electronic Birth Certificate for reporting of screening results to the state database. If your facility uses this method of reporting, you do not need to fill out the scantron “bubbles” on the form. Parents and Primary Care Physician still need to receive their hard copy of the form but no hard copy needs to be sent to the Office of Public Health, as the information on test results and risk factors will be electronically submitted with the birth certificate.

If your hospital does not utilize the electronic birth certificate:

Continue to report the results of the screening on the Newborn Screening Report Form. Be sure to fill out all portions of the form including birth certificate audit number if possible and darken all scantron circles under each letter of the name, date, or risk factor that is identified. Parents and physicians need to receive a hard copy as well as the Office of Public Health.

Training and Monitoring Personnel

If automated equipment is utilized, newborn hearing screening and supervision can be successfully conducted by anyone who receives appropriate training and meets the competency standards. Staffing should allow for all babies to be screened regardless of the day or time that they are born. Additional considerations for staffing and training are as follows:

- Staffing should ensure that no babies are missed: consider 7 days a week, 24 hour a day coverage
- Training should be competency based and involved direct, hands-on components
- Training and supervision must be assured by the Hospital Program Supervisor
- Assessment of screener's skills must include **direct observation of new testers once a month**. Those screeners with at least **one-year experience must be directly observed at least once every three months**.

The number of screeners needed depends on the hospital birth rate and how your program is organized. Programs should ensure that enough people are trained to provide adequate coverage and to maintain the skills needed

Appropriate training of the screening staff to ensure infants are screened appropriately is vital to the success of the program. Your Hospital Program Supervisor should initiate the training and establish screener competency prior to allowing a screener to conduct the screenings.

One-on-one instruction and observation are the most effective method when followed by periodic monitoring and observation of the screener and screening outcomes. **A validation of competency should be completed when competency is met.** A sample competency validation checklist can be found in Appendix D.

After competency is validated, other methods of monitoring screener competency besides direct observation would also be to:

- monitor the pass/refer rate of each individual screener on a monthly basis
- monitor that all hospital and state reporting forms are correctly filled out
- survey parents to determine their satisfaction with technicians explanation of test and test results
- monitor equipment status before and after testing to determine if appropriate procedures of care and storage have been achieved

Hospital Policies and Procedures

Each hospital in Louisiana is unique in the way they serve their community. Each hearing-screening program should reflect this uniqueness in the way that the individual policies and procedures are implemented. Policies and Procedures should be developed in each of the following areas to reflect the practices of your hospital:

Screening Protocols

- ❖ Who should screen, when, and where
- ❖ How to prepare babies for screening
- ❖ The number of screening attempts
- ❖ How long should screeners wait to repeat the screening
- ❖ What to do if the parents refuse screening
- ❖ Infection control
- ❖ Documentation in the medical record

Equipment

- ❖ Troubleshooting equipment
- ❖ What to do if equipment breaks down and who to contact
- ❖ How to order supplies
- ❖ Annual calibration and routine maintenance

Quality Assurance

- ❖ Maintaining records
- ❖ Collecting appropriate documents and information when infant refers
- ❖ Establishing and maintaining method of tracking individual screener's performance
- ❖ Verifying that all babies were screened
- ❖ Measuring benchmarks as suggest in Joint Committee on Infant Hearing statement
- ❖ Measuring of Patient Satisfaction

Follow-up and Tracking

- ❖ Follow-up procedures for infants referred, missed, or at-risk for progressive loss
- ❖ If outpatient follow-up testing is performed by hospital Audiologist
 - Who schedules appointments
 - When and where testing is conducted
 - Reimbursement/preauthorization needed
 - Who should be contacted if a family doesn't return for follow-up
 - Will our facility provide outpatient testing to infants born at other hospitals
- ❖ If outpatient follow-up is not performed by the hospital
 - Who schedules the appointment, nursery staff, pediatrician, etc.
 - When and where will testing be conducted- to which Pediatric Audiologists will we be referring
 - Will parents be able to leave with appointment already made
 - Who is responsible if parent does not attend appointment

Referrals

- ❖ Communication with primary care physician, audiology diagnostic assessment professionals, early intervention, and other local service providers

Quality Assurance and Benchmarks

To ensure a quality program it is also recommended that the Hospital Program Supervisor establish **benchmarks** and **quality indicators** to ensure program efficacy. These should be evaluated monthly and should be consistent with existing data such as those referenced by the Joint Committee on Infant Hearing 2000 Position Statement. The JCIH 2000 recommended benchmarks are:

- 1) Within 6 months of program initiation, hospitals or birthing centers screen a minimum of 95% of infants during their birth admissions.
- 2) The referral rate for audiologic and medical evaluation following the screening process (in hospital during birth admission or during both birth admission and outpatient follow-up screening) should be less than 4% within one year of program initiation.
- 3) If a hospital program offers follow-up testing on outpatients after discharge, the program should retest at least 70% of infants who are referred from initial hearing screening.

JCIH also recommends the following **quality Indicator statistics** for hearing screening programs be compiled. *** In the State of Louisiana, data on the first three quality indicators is being reported on the Newborn Screening Report Form and is tracked through the state database. Information on the last three indicators is gathered from diagnostic centers on a voluntary reporting basis only. It is recommended that hospitals maintain their own data and report it to the Office of Public Health when requested.

- ❖ 1) Percentage of infants screened during birth admission
- ❖ 2) Percentage of infants that do not pass birth admission screening
- ❖ 3) Percentage of families who refuse hearing screening on birth admission
- 4) Percentage of infants screened before 1 month of age if not screened at birth
- 5) Percentage of infants who return for follow-up outpatient rescreening
- 6) Percentage of infants who are referred for further audiologic and medical evaluations

Screening Special Populations

Considerations for screening well-babies with risk factors for late onset or progressive hearing loss or infants with visible malformations must include:

- ❖ Notification of primary care provider and audiologist regarding babies with known risk factors for late onset or progressive loss. Regular audiologic monitoring is recommended beginning at 6 months of age until the child reaches 3 years old. The first appointment can be scheduled prior to discharge from the hospital.
- ❖ Ensuring that families receive informational materials that discuss major milestones in normal speech and language development and risk factors for hearing loss in their native language.
- ❖ Ensuring that families of infants “at-risk” receive information on late-onset or progressive hearing loss as well as local diagnostic resource centers. Risk factors for progressive or late-onset hearing loss can be found in Appendix A.

Communication with Families

Families that understand what is going to happen, are informed of the outcomes, and who understand the next steps are less likely to be overly concerned about the screening results and more likely to follow-up. Communications should be in written and verbal form in the primary language of the home as well as be presented in a culturally competent manner.

Newborn hearing screening is relatively new and it is unlikely that the family is knowledgeable about the procedures or what the tests mean. There are several opportunities to ensure that the families are informed before, during, and after the screening.

Before Screening

Education prior to screening may take the form of information distributed in the birthing classes, brochures in the admission packets or a video on the closed circuit TV. No matter how it is done, it's a good idea to inform the parents before the screening. The Office of Public Health has a video available for use in the hospitals.

During Screening

During the screening, and immediately after, it is critical that the screeners know exactly what they should and should not say. It is important that the screeners know who will tell the parents the results of the hearing screening, when, where, and how. It is not appropriate for the screening technicians to explain the implications of the results unless they have a scripted response prepared by the hospital program supervisor.

After screening

Soon after the screening is done, usually before discharge, the parent should know:

- The results of the screening
- What the results mean
- What should happen now (i.e.: appointment for rescreen or diagnostic follow-up)
- Who will be getting the results (hospitals should consider obtaining a signed consent for local agencies such as Childnet)
- Information about normal development and risk factors for progressive or late onset hearing loss

Ensuring Follow-up

Strategies to help your program ensure that families are not lost to follow-up may include the following:

- ❖ Establish the outpatient rescreening appointment or appointment for further testing at another site at the time of discharge
- ❖ Schedule the next test within 2-4 weeks
- ❖ Coordinate appointments with first well-baby visit if possible
- ❖ Ensure that the parent understands where and when to return for follow-up
- ❖ Ensure that the parent understands who to contact with further questions
- ❖ Record the infant's primary care provider if changing after discharge
- ❖ Provide the medical home with information on follow-up appointments, especially if parents do not keep initial appointment

The most critical component of the early hearing detection and intervention program after the screening is completed, is ensuring that families are not lost to follow-up. Some of the factors that are believed to influence follow-up rates include:

- Parent's understanding of the meaning of the screening outcome and the next steps- the greater the understanding the more compliant the follow-up
- Length of time between birth screening and outpatient screen- less than one month is optimal
- Refer rates- lower refer rates are taken more seriously by the primary care providers as a truly serious result
- Physician support and understanding of how to assist families in obtaining outpatient screen or audiology assessment- physicians need to know where and how to help parents obtain necessary services
- Accuracy of contact information obtained at the time of discharge- multiple phone numbers or contacts is useful in tracking down parents
- Method of communication- some parents prefer written reminders, others phone calls
- Persistence of the Hospital Screening Coordinator in contacting parents that fail to keep appointments- the more attempts the better the chance of follow-up being completed
- Health plans- if infant hearing testing is a covered charge, chances are greater that infant will return for further testing
- Awareness of early hearing detection and intervention in the community- parents that are familiar with the program and its importance will return
- Collaboration with the intervention community- several agencies monitoring follow-up collectively will decrease incidence of "losing" infant to follow-up

Reporting Results and Tracking

Ensuring that the baby and family receive the appropriate assessment and early intervention is a necessary part of the screening process. Without this follow-up, the screening will not result in early hearing detection and intervention.

If a baby refers on initial hospital screening, referrals must be made to:

1. A Pediatric Audiologist experienced in infant testing
2. The Medical Home- usually the primary care physician (PCP)
3. The Office of Public Health, Dept. of Speech, Vision, and Hearing- on the Newborn Hearing Screening Report Form or Electronic Birth Certificate

If a diagnosis of hearing loss is made from diagnostic testing by the pediatric Audiologist, these referrals should also be made :

4. **Further medical referrals** including: ENT and Genetics with report to the Primary Care Physician (Medical Home).
5. Referral to a Pediatric Audiologist that is a **hearing-aid provider**. This can be within the private sector or, if the child qualifies, through Children's Special Health Services, Office of Public Health. Hearing aids should be fit as soon as possible with the goal to begin wearing aids before the child is 3 months old.
6. Local **Childnet** agency- in Louisiana these are located in each local parish school system. A family service coordinator will be chosen and IFSP will be written to provide early intervention services. The goal is to begin appropriate early intervention before 6 months of age. There is no charge for this service.
7. Contact the **Parent Pupil Education Program**- sponsored by the Louisiana School for the Deaf. This agency is located in Baton Rouge, LA. Regional staff composed of teachers of the hearing-impaired outreach to the parents of children with hearing loss immediately upon referral. All children regardless of degree of hearing loss will be accepted. There is no charge for this service. They can be reached at: **Parent-Pupil Education Program, PO Box 3074, Baton Rouge, LA 70821. (888) 769-8111 X331.**
8. **Give parents information** on parent-to-parent support agencies, references or websites on hearing loss, and names and numbers of local parent support groups or key parents to contact.
9. Notify the **Office of Public Health**, Dept. of Speech, Vision, and Hearing using the Follow-up Services Form.

Appendix A: Risk Factors for Progressive Hearing Loss (Taken from the Joint Committee on Infant Hearing Position Statement, 2000)

Any infant with any of the following indicators for progressive or delayed onset hearing loss should receive audiologic monitoring every **six months until age 3 years:**

1. **Parental or caregiver concern** regarding hearing, speech, language, or developmental delay.
2. **Family history of permanent childhood hearing loss.** If a blood relative of the infant had a permanent hearing loss from birth or which began in early childhood and needed a hearing aid or special schooling for the hearing-impaired. This DOES NOT include hearing loss due to illness, ear infections, or aging.
3. **Diagnosis of Neurodegenerative disorders**, such as Hunter's syndrome, Neurofibromatosis, Myoclonic Epilepsy, Wednig-Hoffman Disease, Tay-Sach's Disease, Infantile Gaucher's Disease, Nieman-Pick Disease, any Metachromatic Leukodystrophy or any Infantile Demylinating Neuropathy.
4. **Diagnosis of Congenital (in utero) infections** such as Cytomegalovirus (CMV), Herpes, Rubella, Syphilis, Epstein-Barr Virus, HIV, or Toxoplasmosis.
5. **Use of Prolonged Mechanical Ventilation** -if the infant had mechanical ventilation for 5 days or greater, persistent pulmonary hypertension of the newborn associated with mechanical ventilation, persistent fetal circulation, or a condition requiring use of extracorporeal membrane oxygenation (ECMO).
6. **Use of Ototoxic Drugs for more than 5 days** including but not limited to aminoglycosides (Gentamicin, Tobramycin, Kanamycin, Streptomycin) especially in combination with Loop Diuretics.

Appendix B- Participants

These guidelines were developed with assistance from the following participants:

Department of Health and Hospitals:

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Region V Task Force (Lake Charles)- Steve Morris, Coordinator
Region VI Task Force (Alexandria)- Ashley Lammons, Coordinator
Region VII Task Force (Shreveport)- Leigh Ann Norman, Coordinator
Region VIII Task Force (Monroe)- Debbie Cowan, Coordinator
Region IX Task Force (Hammond)- Kristy Hoffecker, Coordinator

These task force groups consist of members from the following agencies and disciplines:

Audiologists, Childnet/Childsearch Pupil Appraisal Educators, Deaf services providers, Early Interventionists, Family Service Coordinators, Hospital Administrators, Louisiana Association for the Deaf representatives, Nurses, Nurse practitioners, Otolaryngologists, Parents of hard of hearing children, Parent Pupil Educator Program representatives, Physicians, Social workers, Speech Therapists, Sign-language interpreters, Teachers of the hearing-impaired, and University Program Coordinators.

These guidelines were developed in part by funds from grants from the Maternal and Child Health Bureau, and the National Center for Disease Control. Thanks to all who participated in the process.

Appendix C: Legislation/ Rules and Regulations

- C1. Act 653 of 1999 (universal hearing screening legislation)
- C2. DHH/OPH Rules and Regulations, 2001
- C3. Louisiana State Licensing Board (LBESPA) rule on Audiology Assistants, 2002.
- C4. DHH/OPH Sound Start Program Newborn Hearing Screening Report Form
- C5. Sample Audiology Assistant competency validation record
- C6. Sample Policy and Procedures
- C7. Sample Parent Letter
- C8. Follow-up Services Form and instructions
- C9. Electronic Birth Certificate instructions for state reporting